

***MR/DD Quality of Life Interview
CONSUMER SURVEY
Version 2.0***

June 2003

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Description of Project:

This survey was developed in conjunction with the **Core Indicators Project**, co-sponsored by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the project is to identify and measure **core indicators** of performance of state developmental disabilities service systems. The project is currently in its fifth year, with a total of twenty-three states participating. This survey is intended to measure a subset of the performance indicators identified by the project Steering Committee, made up of representatives from the participating states.

Organization of Survey:

The survey consists of five sections.

- ✧ The **Pre-Survey Form** requests information that may be used by the interviewer to schedule and conduct the interviews.
- ✧ The **Background Information** section requests information that will be analyzed in conjunction with the interview responses. This information must be collected for all individuals surveyed.
- ✧ **Section I** contains questions that may only be answered by face-to-face interviews with the person receiving services and supports. These are subjective, "satisfaction" related questions that may not be answered by anyone else.
- ✧ **Section II** contains questions that may be answered by someone who knows the person well, such as a family member, friend, staff person, guardian or advocate. Interviews with other respondents may be conducted either in person or over the phone.
- ✧ The **Interviewer Feedback Sheet** is the last page of the survey. Please fill out one sheet for each interview you complete.

You may print additional copies of this survey by going to: www.state.me.us/bds/ and go to the Office of Quality Improvement.

Pre-Survey Form

This pre-survey form should be completed by the state or surveying organization using appropriate information sources, such as state data systems, case managers/service coordinators, or providers. The interviewer will then use this information to schedule and conduct the interview.

Name of person completing this form: _____

(In order to administer this survey, you must have attended a BDS training after February 2, 2003. If you have any questions you may contact BDS' Office of Quality Improvement at 287-4210)

Date: _____

Consumer's Name: _____

Medicaid ID #: _____

Gender: ____ Male ____ Female

Consumer's Phone: _____ - _____

Consumer's Home address:

Street

City

State

Zip

Agency/Organization Name: _____

Agency/Organization Address: _____

Street

City

State

Zip

Did consumer give consent for interview? ____ Yes ____ No

Did guardian give consent for interview? ____ Yes ____ No ____ N/A

Please attach copy of consent form.

- PS-1. **Communication needs...** Does this person have any special communication needs? (Example: primary language other than English, sign language, communication board.) Please explain what arrangements were needed for the interview.

- PS-2. **Other Interviewees...** If this person is unable or unwilling to complete Section II of the survey, please indicate the name(s) and number(s) of others who responded on his/her behalf.

Name: _____ Relationship: _____

Daytime Phone: _____ Evening Phone : _____

Name: _____ Relationship: _____

Daytime Phone: _____ Evening Phone : _____

- PS-3. **Job/Day Activities...** If applicable, please indicate what this person calls his/her job, school or day activity program.

Place of work: _____

School: _____ Day program: _____

BACKGROUND INFORMATION

Please indicate who provided this information: (check all that apply)

- ☐ 2 Advocate, Parent, Guardian, Personal Representative, Relative
- ☐ 3 Staff who provides supports where person lives
- ☐ 4 Staff who provides supports at a day or other service location
- ☐ 5 Case Manager, service coordinator, social worker
- ☐ 6 Other person
- ☐ 7 State data system

HEALTH

BI-20. When was his/her last physical exam? (check one)

- ☐ 1 Within the past year
- ☐ 2 Over one year ago
- ☐ 3 Don't know or not available in records

BI-21. When was her last OB/GYN exam? (check one)

- ☐ 0 NOT APPLICABLE -- male
- ☐ 1 Within the past year
- ☐ 2 Over one year ago
- ☐ 3 Has never had an OB/GYN exam
- ☐ 4 Don't know or not available in records

BI-22. When was his/her last dentist visit? (check one)

- ☐ 1 Within the last six months
- ☐ 2 Over six months ago
- ☐ 3 Don't know or not available in records

RESIDENCE

BI-23. How many different places has this person lived within the past year? (Present home counts as one. Do not include moves within the same facility.)

___ Number of places

BI-24. How would you characterize the place where this person lives?

(check one)

- ☐ 1 Specialized institutional facility for persons with MR/DD (includes ICFs/MR)
- ☐ 2 Group home
- ☐ 3 Agency-operated apartment type setting (**agency** owns or leases the apartment)
- ☐ 4 Independent home or apartment (agency may provide support, but **person** owns or leases the home)
- ☐ 5 Parent/relative's home
- ☐ 6 Foster care or host home (person lives in home of unrelated, paid caregiver)
- ☐ 7 Nursing facility
- ☐ 8 Other (specify) _____
- ☐ 9 Don't know

BI-25. Who owns or leases the place where this person lives? (check one)

- ☐ 1 Family, guardian, or friend
- ☐ 2 Private agency or home provider/foster family
- ☐ 3 State or County agency
- ☐ 4 Person rents home (name is on the lease)
- ☐ 5 Person owns home (name is on the title)
- ☐ 6 Don't know
- ☐ 7 Other

FEATURES OF SELF-DETERMINATION

BI-30. Does this person currently have...? (check one column for each):

no	yes	don't know
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___ 1	___ 2	___ 3	an individually negotiated budget -- the individual and his/her circle of support have control over and knowledge of how much is spent on that person's behalf and what it is being spent on
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___ 1	___ 2	___ 3	a person-centered plan -- a service plan developed by the individual and his/her circle of support, often with help from a facilitator
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- __ 1 __ 2 __ 3 **a relationship with a fiscal intermediary or intermediary service organization** -- organizations that act as “employers of record” or “co-employers” for an individual who hires his/her own staff
- __ 1 __ 2 __ 3 **a “microboard” that manages his/her funds** -- a group of families responsible for administering a block of funds for several individuals
- __ 1 __ 2 __ 3 **a support broker or personal agent** -- an independent agent who is hired to negotiate services or supports for an individual

DAY / VOCATIONAL / EDUCATIONAL SUPPORT

The table below lists six types of vocational/employment services and other day supports.

Please see the next two pages for definitions of terms used on this form.

For the most recent month possible, please enter

a) number of hours worked or spent in each activity; and

b) total wages earned for each category of paid work.

	a) Number of hours at this activity in the last month	b) Total wages earned in the last month
S1. Competitive Employment	— — —	\$ — — — . — —
S2. Individual Supported Employment	— — —	\$ — — — . — —
S3. Group Supported Employment	— — —	\$ — — — . — —
S4. Facility-Based Work Programs	— — —	\$ — — — . — —
S5. Facility-Based Non-Work Activities	— — —	N/A
S6. Community-Based Non-Work Activities	— — —	N/A

S7. Is this person enrolled in the public school system?

__ (1) No

__ (2) Yes

S8. What agency or program pays for the day / vocational services this person receives? Please check all that apply.

__ (1) HCBS Waiver Program (including Federal + State Match)

__ (2) State MR/DD Agency

__ (3) Vocational Rehabilitation Agency

__ (4) PAS/IRWE Plan (person is buying some of his/her own supports)

__ (5) Other

__ (6) Not applicable – person does not receive any day / vocational services

Community Employment – If the person has a job in the community (either competitive or supported employment), please answer the following questions:

S9. Did this person work 10 out of the last 12 months in a community job? (Person may have changed jobs or had periods of unemployment/transition.)	(circle one) Yes No N/A
S10. Does this person receive benefits at his/her community job? (e.g. paid vacation, sick time, health insurance)	(circle one) Yes No N/A
S11. How long has this person been working at his/her current job in the community?	— — years — — months

DEFINITIONS

The term “day supports” means the regular provision of publicly funded training and other assistance to adults with developmental disabilities outside their living arrangement. Day supports include services that are work-oriented, habilitative in nature and/or intended to promote community presence and participation.

For reporting purposes, we have defined six generic subcategories of day supports and other employment.

- **Competitive Employment.** [*This is not a service or support, therefore is not listed in BI-28.*] Individuals have a job of their own in the community but are not receiving “supported employment” – that is, they do not routinely receive community job supports or job coaching. They may have access to supports as needed or may receive “follow-along” but is basically working on their own.
- **Individual Supported Employment.** [*Called “Vocational – supported employment” in BI-28.*] Individuals have a job with a community employer and receive periodic publicly-funded assistance, training and support aimed at securing and/or maintaining employment and/or improving job skills.
- **Group Supported Employment.** [*Called “Vocational – group employment” in BI-28.*] Two or more individuals are employed by a community provider agency and perform work as employees of the provider agency at sites in the community

(e.g., mobile crews). Group supported employment also includes persons who are employed in an affirmative industry or as part of an enclave.

- **Facility-based Work Programs.** [*Called “Vocational – facility based” in BI-28.*] Take place in settings such as sheltered workshops or work activity centers. Individuals are paid a wage in exchange for their production-related activities. They are employed by the provider agency.
- **Facility-Based Non-Work Activities.** [*Called “Non-vocational day service – facility based” in BI-28.*] Take place at a provider facility and involve the provision of training and other services and supports that are not paid work. These services are commonly labeled “day habilitation,” “day training,” or “day treatment.” Seniors programs and job training programs also fall into this category.
- **Community-Based Non-Work Activities.** [*Called “Community participation / accessibility connections” in BI-28*] Includes the provision of training and assistance that enables individuals to participate in community activities, by serving as volunteers, recreating and/or learning skills important for community living. These activities take place away from provider-operated facilities.
- **Total Wages.** Wages earned means the total gross amount (before deductions) actually paid to individuals during the last month. In some cases, there is a difference between the wage rate charged to the business where the person works and the amount actually paid to the individual (e.g., the provider agency functions as an “employment agency” and charges the community business a higher hourly rate than the rate paid to the individual). For data collection purposes, the amount reported should be the total amount paid to individuals by type of day support during the most recent month for which data is available.
- **Number of Hours at this Activity.** For the various work categories, the total number of hours of compensated work during the last month should be reported.

Please note: In the case of individuals who are working in a facility, time in the facility when the person is not earning a wage (e.g., is not engaged in work) should be counted as hours of facility-based non-work activity. For example, if a person is at a facility for 126 hours during the month and is engaged in paid work for 83 hours, the remaining 43 hours would be reported as facility-based non-work activities.

SECTION I: Direct Interview with Person Receiving Services and Supports

General Instructions:

- ✧ This section may only be completed by **directly interviewing the person receiving services and supports.**
- ✧ Do not use responses from any other person to complete this section.
- ✧ If the person receiving services does not respond to a question or gives an unclear response, code the question as “9.”
- ✧ Remember to ask questions in the order that they are written. Do not skip questions or leave any questions blank.
- ✧ Be sure to read all instructions carefully.
- ✧ If possible, the interview should be conducted in private. Parents or guardians may be present if they insist. Others may be present if the consumer requests it, or if another person is needed for interpretation purposes. If staff believe that a private interview may pose risks to interviewers, then staff should be present. If others are providing assistance, interviewers should emphasize that we are trying to find out the consumer's perspective.
- ✧ You must read the question exactly as written. If the consumer does not understand the question, you may rephrase the question once. If the consumer does not understand the question after rephrasing, you will document the response option “no response, unclear response, don’t know.”
- ✧ You do not provide the consumer with the response options. Upon the consumer answering the question, you will need to probe for information and document the response option that best fits the information provided to you by the consumer.
- ✧ Document only one response option per question.
- ✧ Prior to the interview, interviewers should use the pre-survey form to fill in the blanks throughout the survey. Using familiar names and terms during the interview will help ensure that the person understands the questions.
- ✧ If you have questions concerning the intent of a survey question, refer to the list of Core Indicators in your training packet.

- ✧ A wide margin is provided for recording notes as necessary. Please be sure to fill out the **Interviewer Feedback Sheet** after each interview.

Work/Daytime Activities

For Questions 1-2, include all types of work and daytime activities - paid, unpaid, community-based jobs, supported employment, facility-based jobs, day programs, volunteer work, non-vocational programs, training facilities, etc. If respondent has more than one job/day activity, ask how s/he feels in general or "most of the time." If respondent works and attends school, ask about work only.

- 1. I'd like to start by asking you about what you do during the day – if you have a job or other place that you go to.**

Do you work at (go to) _____?

Do you like working (going) there?

- ☐ 8 NOT APPLICABLE – no job or day activity
- ☐ 2 Yes
- ☐ 1 In-between
- ☐ 0 No
- ☐ 9 Don't know, no response, unclear response

- 2. Do you have staff who help you there?**

Does _____ help you there?

If the person does not have staff at the job or day activity or is in competitive employment, code Question 2 as "NOT APPLICABLE."

Is s/he nice and polite to you?

- ☐ 8 NOT APPLICABLE - no job or day activity or no staff
- ☐ 2 Yes, most staff are nice
- ☐ 1 Some staff are nice
- ☐ 0 No, most staff are not nice
- ☐ 9 Don't know, no response, unclear response

3. Are you feeling happy or sad today?

This is a consistency check question – do not rephrase.

- __2 Happy
- __1 In-between
- __0 Sad
- __9 Don't know, no response, unclear response

HOME

Now I'm going to ask you about where you live.

4. Do you like your home or where you live? *(Do you like living here?)*

- __2 Yes
- __1 In-between
- __0 No
- __9 Don't know, no response, unclear response

5. Can you be alone if you want to? *(Can you have privacy?)*

Here we are looking at privacy (e.g. going in a room and closing the door), not the person's need for supervision (e.g. staying home alone).

- __8 NOT APPLICABLE - lives alone
- __2 Yes, has enough time alone
- __0 No, would like more time alone
- __9 Don't know, no response, unclear response

6. Are you ever afraid or scared when you are at home?

- __2 [Yes] - most of the time
- __1 Sometimes
- __0 [No] - rarely
- __9 Don't know, no response, unclear response

7. Are you ever afraid or scared when you are out in your neighborhood?

- ☐_2 [Yes] - most of the time
- ☐_1 Sometimes
- ☐_0 [No] - rarely
- ☐_9 Don't know, no response, unclear response

8. Do you have staff who help you where you live?

Does _____ help you at home?
Is s/he nice and polite to you?

- ☐_8 NOT APPLICABLE – no home support staff
- ☐_2 Yes
- ☐_1 Sometimes
- ☐_0 No
- ☐_9 Don't know, no response, unclear response

9. Do people (including staff) let you know before they come into your home? *(Do they ring the doorbell or knock first and wait for an answer?)*

- ☐_2 Yes
- ☐_1 Sometimes
- ☐_0 No
- ☐_9 Don't know, no response, unclear response

10. Do people (including staff) ask permission before coming into your bedroom?

- ☐_2 Yes, unless it's an emergency
- ☐_1 Sometimes
- ☐_0 No
- ☐_9 Don't know, no response, unclear response

11. Let me check - are you feeling sad or happy today?

This is a consistency check question – do not rephrase.

- __2 Happy
- __1 In-between
- __0 Sad
- __9 Don't now, no response, unclear response

FRIENDS AND FAMILY

12. Now I'm going to ask you about friends.

Do you have friends you like to talk to or do things with?

If s/he answers "yes," ask who the friends are and try to determine if they are family, staff, roommates, co-workers, etc. You can use prompts such as: *Can you tell me their names? Are these friends staff or your family?*

- __2 Yes, has friends who are not staff or family
- __1 Yes, all friends are staff or family, or cannot determine
- __0 No, does not have friends
- __9 Don't know, no response, unclear response

If the person responds "NO" TO QUESTION 12, code Questions 13-14 as "NOT APPLICABLE." Also code Question 45 as "NOT APPLICABLE."

13. Do you have a best friend, or someone you are really close to? (Is there someone you can talk to about personal things?)

It doesn't matter if they are family or staff here.

- __8 NOT APPLICABLE - does not have friends
- __2 Yes
- __0 No
- __9 Don't know, no response, unclear response

14. Can you see your friends when you want to see them? (*Can you make plans with your friends when you want to?*)

We are trying to determine if person gets support to see friends. Try to factor out situations where friends are not available – this is not the issue.

- __8 NOT APPLICABLE – does not have any friends
- __2 Yes, can see friends whenever s/he wants to
- __1 Sometimes can't see friends (e.g. not enough staff or transportation)
- __0 No, often unable to see friends
- __9 Don't know, no response, unclear response

15. Do you ever feel lonely?

If s/he responds "yes," probe to determine how often s/he feels lonely.

- __2 [Yes] – often feels lonely
- __1 Sometimes
- __0 [No] – not often
- __9 Don't know, no response, unclear response

16. Do you have family that you see?

If the person lives with family, ask about other family members that do not live in the home.

Can you see your family when you want to? (*Can you pick the times you see them? Does someone help you make plans to see them?*)

If family is not available or does not wish to have contact, code as "NOT APPLICABLE." If the person has family but does not want to see them, code as "2."

- __8 NOT APPLICABLE – family not available or family does not wish to have contact
- __2 Yes, sees family whenever s/he wants to, or chooses not to see family
- __1 Sometimes
- __0 No
- __9 Don't know, no response, unclear response

SERVICES/SUPPORTS COORDINATION

ASK QUESTIONS 17-19 ONLY IF PERSON HAS AN INDIVIDUAL SUPPORT COORDINATOR THROUGH BDS. If person does not have an Individual Support Coordinator thru BDS, code these questions as "NOT APPLICABLE". If the person has a Individual Support Coordinator through BDS but says they do not or do not know him/her, code questions 17-19 as "0."

17. Do you know your Individual Support Coordinator?

- ☐ 8 NOT APPLICABLE – person does not have an Individual Support Coordinator
- ☐ 2 Yes, person knows Individual Support Coordinator
- ☐ 1 Maybe, not sure
- ☐ 0 No, person does not know Individual Support Coordinator
- ☐ 9 Don't know, no response, unclear response

18. If you ask for something, does s/he help you get what you need?

- ☐ 8 NOT APPLICABLE – person does not have Individual Support Coordinator, or person does not ask for help
- ☐ 2 Yes, does help
- ☐ 1 Sometimes helps
- ☐ 0 No, does not help or person does not know Individual Support Coordinator
- ☐ 9 Don't know, no response, unclear response

19. Does s/he ask you what you want?

- __8 NOT APPLICABLE – person does not have Individual Support Coordinator, or person does not talk to case manager
- __2 Yes
- __1 Sometimes
- __0 No, does not ask or person does not know Individual Support Coordinator
- __9 Don't know, no response, unclear response

20. Do you have a guardian or someone who can speak on your behalf?

.....

- __8 NOT APPLICABLE – has no advocate or is own guardian
- __2 Yes
- __1 Maybe, not sure
- __0 No
- __9 Don't know, no response, unclear response

21. Do people help you do new things you want to do?

- __2 Yes, people always help
- __1 People sometimes help
- __0 No, people never help
- __9 Don't know, no response, unclear response

22. When you want to go somewhere, do you always have a way to get there? (Can you get a ride when you need one?)

- __2 Yes, almost always
- __1 Sometimes
- __0 No, almost never
- __9 Don't know, no response, unclear response

23. Interviewer: Could Section I be completed?

- ☐__1 Yes, person answered independently or with some assistance
- ☐__2 Yes, person answered using alternative/picture response format
- ☐__3 No, person could not communicate sufficiently to complete this section
- ☐__4 No, person was unwilling to participate
- ☐__5 No, other reason

24. Interviewer: In your opinion, did the individual understand most of the questions or not?

- ☐__8 **NOT APPLICABLE** – did not complete
- ☐__2 Yes, understood most questions (even if prompted) and could give an opinion
- ☐__1 Not sure
- ☐__0 No, very little understanding or no comprehension

25. Interviewer: In your opinion, did the individual answer the questions in a consistent manner? (Do you feel his/her responses were valid?)

- ☐__8 **NOT APPLICABLE** – did not complete
- ☐__2 Yes, gave consistent and valid responses
- ☐__1 Not sure
- ☐__0 No, did not give consistent and valid responses

SECTION II: Interview with the Person Receiving Services or with Other Respondents

Interview the person receiving services if possible. If you are unable to interview the person, other respondents may be interviewed (family, advocate, staff) if they are knowledgeable in the areas below. If the person receiving services has completed Section I, but has become tired or does not wish to continue with this section, you may interview other persons. Use alternative wording when questioning other respondents. Also, check the appropriate box to indicate who is responding.

Remember, there is not an interviewer rating sheet at the end of Section II to rate the individual's understanding or accuracy of answers. Therefore, it is important that valid answers are documented. You may write other opinion's in the margin.

Ask the person if s/he wishes to continue with the questions, or if s/he would like to take a short break.

COMMUNITY INCLUSION

In this section, we are trying to find out if the person participates in integrated activities. Try to rule out non-integrated activities, for example, Special Olympics. If the person answers "yes," you may ask for an example to verify that the person understood the question.

- 26. Do you (does this person) go shopping?** *(What do you go shopping for? Examples: groceries, clothing, house-wares, tapes/CDs.)*

Indicate respondent: () 1-consumer () 2-other

__2 Yes
__0 No
__9 Don't know

- 27. Do you (does this person) go out on errands or appointments?** *(Where do you go? Examples: doctor, dentist, bank, post office, hair dressers/barber.)*

Indicate respondent: () 1-consumer () 2-other

__2 Yes
__0 No
__9 Don't know

- 28. Do you (does this person) go out for entertainment?** *(Where do you go? Examples: movies, library, plays, concerts, museums, art galleries.)*

Indicate respondent: () 1-consumer () 2-other

__2 Yes
__0 No
__9 Don't know

29. Do you (does this person) always eat at home, or do you sometimes go out to eat? *(What restaurants do you go to?)*

Indicate respondent: () 1-consumer () 2-other

- __2 Sometimes goes out to eat
- __0 Always eats at home
- __9 Don't know

30. Do you (does this person) go to religious services? *(Where do you go? Examples: church, synagogue, or other place of worship.)*

Indicate respondent: () 1-consumer () 2-other

- __2 Yes
- __0 No
- __ No, chooses not to go to religious services
- __9 Don't know

31. Do you (does this person) go to clubs or other community meetings? *(Where do you go? Examples: non-religious clubs, social groups or community organizations.)*

Indicate respondent: () 1-consumer () 2-other

- __2 Yes
- __0 No
- __9 Don't know

32. Do you (does this person) exercise or play sports? *(What kind of exercise? Examples: jogging, swimming, riding bike, etc.)*

Indicate respondent: () 1-consumer () 2-other

- __2 Yes, in a community setting
- __1 Yes, gets exercise but in a non-integrated setting
- __0 No
- __9 Don't know

CHOICES

The intent of these questions is to determine if persons receiving services are involved in decision-making.

- In this section, code "2" only if you can convince yourself that this person made a real choice. Code "1" if you think the person had some input in making the decision.
- Choices made with spouses/partners should be coded as "without help."
- Do not overuse the "NOT APPLICABLE" code here. It is not appropriate to use "8" to indicate NOT ALLOWED or NOT CAPABLE of making decisions in this area. There is a code for indicating that someone else made the decision.

Read one of the following introductions to the respondent(s):

For Consumers:

I'm going to ask you questions about some decisions you may have made or helped make. For each question, I'd like you to tell me if you made the choice by yourself, if you had some say about it, or if someone else decided for you.

For Other Respondents:

I'm going to ask some questions now about decisions this person may have made. For each question, please indicate if s/he made the decision independently, if s/he had some input in making the decision, or if someone else made the decision for him/her.

If the person lives with his/her family, code questions 33-35 as "NOT APPLICABLE."

33. Who chose (or picked) the place where you live? *(Did you choose by yourself or with help?)*

(Other respondent: Who chose the place where s/he lives? Did s/he have any input in making the decision?)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE – lives with family
- __2 Person chose without help
- __1 Person had some input
- __0 Someone else chose
- __9 Don't know

34. How many places did you visit before moving here?

(Other respondent – How many places did s/he look at before moving in?)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE – lives with family
- __2 Looked at more than one place
- __1 Visited one place only
- __0 Did not visit before moving in
- __9 Don't know, can't remember ---too long ago

- 35. Did you choose (or pick) the people you live with (or did you choose to live by yourself)?** *(Did anyone ask you who you'd like to live with? Were you given choices, did you get to interview people?)*

Did you choose to live with _____ ?

*(Other respondent – Did this person choose any of the people s/he lives with?
Or: Did this person choose to live alone?)*

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE – lives with family
- __2 Yes, chose people s/he lives with, or chose to live alone
- __1 Chose some people or had some input
- __0 No, someone else chose
- __9 Don't know

- 36. Do you choose (or pick) who helps you at home?** *(Do you get to interview them? Did you get to meet different people or was someone assigned to you? If you wanted to change, could you ask for someone different?)*

Did you choose _____ to work with you?

(Other respondent – Does this person choose his/her residential staff?)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE - no staff in the home
- __2 Yes, person chooses staff
- __1 Staff are assigned but s/he can request a change if not satisfied
- __0 No, someone else chooses
- __9 Don't know

37. Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?

(Other respondent – Who decides this person's daily schedule, like when to get up, when to eat, when to go to sleep?)

Indicate respondent: () 1-consumer () 2-other

- __2 Person decides
- __1 Person has help deciding
- __0 Someone else decides
- __9 Don't know

38. Who decides how you spend your free time (when you are not working, in school or at the day program)?

(Other respondent – Who decides how this person spends his/her free time?)

Indicate respondent: () 1-consumer () 2-other

- __2 Person decides
- __1 Person has help deciding
- __0 Someone else decides
- __9 Don't know

NOTE: For Questions 39-41, do not include school. If respondent works and attends school, ask about work only.

39. Who chose (or picked) the place where you work (or go during the day)? *(Did you choose by yourself or with help?)*

Did you choose to work at (go to)_____?

(Other respondent: Who chose the place where s/he works or goes during the day? Did s/he have any input in making the decision?)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE – no work or day activity
- __2 Person chose without help
- __1 Person had some input
- __0 Someone else chose
- __9 Don't know

40. How many places did you visit before working (going) there?

(Other respondent – How many places did s/he look at before working/going there?)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE – no work or day activity
- __2 Looked at more than one place
- __1 Visited one place only
- __0 Did not visit beforehand
- __9 Don't know, can't remember – too long ago

- 41. Do you choose (or pick) who helps you at work?** *(Do you get to interview them? Was someone assigned to you? Could you request someone different?)*

Did you choose _____ to help you at work?
(Other respondent – Does this person choose his/her work/day activity staff?)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE - no job or day activity staff
- __2 Yes
- __1 Some staff, or staff are assigned but s/he can request someone different
- __0 No
- __9 Don't know

- 42. Do you choose what you buy with your spending money?**
(Do not include things like rent or groceries.)
(Other respondent – Does this person choose how to spend his/her money?)

Indicate respondent: () 1-consumer () 2-other

- __2 Person chooses
- __1 Person has help choosing what to buy, or has set limits (such as can buy small items, but not big items)
- __0 Someone else chooses
- __9 Don't know

43. Did you choose or pick your Individual Support Coordinator?

Did you choose _____ to work with you?

(Other respondent – Did this person choose his/her Individual Support Coordinator from BDS.)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE - no Individual Support Coordinator
- __2 Yes, chose Individual Support Coordinator
- __1 Individual Support Coordinator was assigned but s/he can request a change if not satisfied
- __0 No, someone else chose Individual Support Coordinator
- __9 Don't know

RIGHTS

44. Do people read your mail without your permission?

(Other respondent – Does anyone read this person's mail without permission?)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE - does not get mail
- __2 [Yes] – mail is always read without permission
- __1 Some mail is read without permission
- __0 [No] – person reads own mail or others read with permission
- __9 Don't know

45. Do your friends ever come over to visit?

If no, code as "NOT APPLICABLE." If yes, ask:

Can you be alone with them, or does someone have to be with you? *(Are there rules about having friends over?)*

(Other respondent – can this person have privacy to be alone with friends when s/he wants to, or does someone else have to be present?)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE – no friends or friends do not visit
- __2 Can be alone with friends
- __1 There are some rules (e.g only in common areas, or not overnight)
- __0 Someone else always has to be present
- __9 Don't know

46. Are you allowed to use the phone when you want to?

(Other respondent – is this person allowed to use the phone when s/he wants to?)

If person is unable to use the phone or doesn't have access to a phone/TTY, code as "NOT APPLICABLE."

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE - doesn't have phone/TTY or unable to use phone
- __2 Yes, can use anytime, either independently or with assistance, has own phone, or uses email
- __1 There are some rules/restrictions on use of phone
- __0 No, person is not allowed to use phone
- __9 Don't know

47. Have you ever participated in a self-advocacy group meeting, conference, or event? *(A self-advocacy group is where people meet together to talk about things in their lives that are important to them.)*

(Have you ever gone to a _____ meeting or event?)

(Other respondent – Has this person ever attended a self-advocacy group meeting or event?)

Indicate respondent: () 1-consumer () 2-other

- __8 NOT APPLICABLE – there is no self-advocacy group in the area
- __2 Yes
- __1 Had the opportunity but chose not to participate
- __0 No
- __9 Don't know

ACCESS

48. Do you get the services you need?

We are only looking for services and supports here, such as transportation, job coaching, taking a class, getting medical care, etc.

(Other respondent – Does this person get the services and supports s/he needs?)

Indicate respondent: () 1-consumer () 2-other

- __2 Yes
- __1 Sometimes, or doesn't get enough of the services needed
- __0 No
- __9 Don't know

If no, what services are needed?

49. Interviewer: Please indicate who completed this section
(check all that apply):

- ☐__1 Person receiving services
- ☐__2 Advocate, Parent, Guardian, Personal Representative,
Relative
- ☐__3 Staff who provides supports where person lives
- ☐__4 Staff who provides supports at a day or other service
location
- ☐__5 Other

INTERVIEWER FEEDBACK SHEET

Instructions to interviewers:

Please take a few minutes to complete a feedback sheet after each interview you complete.

Interviewer's Initials or Code (optional): _____

1. How long did it take to complete the direct interview(s) (Sections I and II only)?

__ __ **Hours** __ __ **Minutes**

2. How long did it take to complete the entire form, including phone-calls, collecting background information, arranging and conducting the interviews, travel time, etc.?

__ __ **Hours** __ __ **Minutes**

3. Were there any questions that were problematic?

__ **Yes** __ **No**

If yes, indicate the question number(s) below and describe the problem and any suggestions you have for improvement.

Question: Problem/Suggestions:

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Other Comments:
